

Chapter 2: Introduction to the 2006 UK Renal Registry Report

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The UK Renal Registry is part of the UK Renal Association and provides independent audit and analysis of renal replacement therapy (RRT) in the UK. The Registry is funded directly by participating renal units through an annual fee per patient registered.

The Registry is now collecting data on incidence and prevalence from 100% of UK renal units, with the 5 remaining non-linked sites in England providing summary data.

Maintaining and enhancing Registry functionality will be an important touchstone for the Connecting for Health initiative. Collaboration with other formal agencies also promises an exciting prospect for future development. After a long proving period, the means, methods and roles have come together to complete an effective adjunct to clinical activity, planning, research and the performance of the renal community.

Quality Improvement

Provision of evidence of important variations in the outcomes of RRT is not, by itself, sufficient to result in reduction of variation. For this reason, the variations that the Registry reports between renal units around the UK remain, at least for some markers, remarkably stable over time. It is easy for clinicians in 'under-performing' units to ignore the analyses – arguing, for instance, that case mix explains the variation ("my patients are different"), or differences in funding, or differences in infrastructure – or just that the data are wrong. The first challenge therefore, is to persuade clinicians to accept that the data reflect real differences. Over time, the Registry Reports have gained increasing acceptance, and many now believe that the differences are real, and susceptible to improvement within existing funding. In this sense, the Registry Reports provide the 'tension for change'. The second

challenge is to discover the reasons – the differences in practice patterns, treatment strategies, funding arrangements and policies that cause the variations – while acknowledging that different strategies may work in different units, depending on staffing, geography and culture. The third challenge is to reduce variation and to improve the overall standard of care provided to patients on RRT throughout the UK.

These are new challenges for the UK Renal Registry. The science of quality improvement incorporates evidence-based medicine, but also involves understanding of the sociology and psychology of change. The Registry is launching a year-long web-based collaborative quality improvement project at the forthcoming meeting of the multidisciplinary British Renal Society (BRS) in June 2007, in collaboration with the NHS Institute for Innovation and Improvement. The design of this project draws on the Institute for Healthcare Improvement's collaboratives. This will focus on two topic areas, control of serum phosphate and correction of renal anaemia. Renal units have been invited to send multidisciplinary teams working in each of these areas to the BRS meeting. The meeting will comprise a 'crash course' in how to achieve quality improvement in the NHS, followed by sessions devoted to 'change packages' developed in each clinical area by a faculty drawn from renal units whose performance against Renal Association standards in each clinical area has been consistently high. Teams will then be expected to test implementation of new systems of care, protocols and treatment algorithms and to share their experience on a password-protected area in a new website, www.nhs.uk/collaborate, designed to promote such interactions.

With the presentation of these Registry analyses to the renal community, the challenge to UK nephrology remains, to find effective and creative ways of using the analyses to understand and reduce variations in clinical

practice. The necessary formal structures are now in place to allow full value to be derived from the opportunities provided by the Registry data. The Registry is committed to developing added value to the collected data through novel means of presentation and analysis. This commitment has gained increasing acceptance and recognition. With external pressures for increasing diversity of renal provision in England, a more formal role for the Registry within NHS structures appears likely to help monitor this new service provision.

Geographical areas covered by the UK Renal Registry

The full participating centres are shown in Table 2.1.

The Scottish Renal Registry provided demographic and also haematology and dialysis dose

data from the whole of Scotland.

All the above renal units in England & Wales and also the Scottish Registry run the CCL Proton software, except:

Ipswich and Bangor (Baxter system), Aberdeen, Brighton & Newcastle (CCL clinical vision), Kings, The London and Royal Free (Renalware), Airdrie, Basildon, Chelmsford, Dorset, Dundee, Norwich, all five Northern Ireland units (Mediqal eMed), Shrewsbury & Stevenage (Renalplus) and Birmingham QEH, Hammersmith & Hope Hospital (own systems).

Cambridge are in the process of changing their renal IT system to in-house software; Derby are in the process of changing their renal IT system to Vitaldata; Wirral are developing in-house software; Wrexham are in the process of changing their renal IT system to Renalplus.

Table 2.1: Centres in the 2006 Registry Report

Hospital		Estimated population (Millions)
England & Wales		46.55
Bangor	Ysbyty Gwynedd	0.18
Basildon	Basildon Hospital	0.50
Birmingham	Heartlands Hospital	0.60
Birmingham	Queen Elizabeth Hospital	1.82
Bradford	St Luke's Hospital	0.60
Brighton	Royal Sussex County Hospital	0.98
Bristol	Southmead Hospital	1.50
Cambridge	Addenbrookes Hospital	1.42
Cardiff	University of Wales Hospital	1.30
Carlisle	Cumberland Infirmary	0.36
Carshalton	St Helier Hospital	1.80
Chelmsford	Broomfield Hospital	0.50
Clwyd	Ysbyty Clwyd	0.15
Coventry	Walsgrave Hospital	0.85
Derby	Derby City Hospital	0.48
Dorset	Dorchester Hospital	0.71
Dudley	Russell's Hall Hospital (previously Wordsley)	0.42
Exeter	Royal Devon and Exeter Hospital	0.75
Gloucester	Gloucester Royal Hospital	0.55
Hull	Hull Royal Infirmary	1.04
Ipswich	Ipswich Hospital	0.33
Leeds	St James's Hospital & Leeds General Infirmary	2.20
Leicester	Leicester General Hospital	1.80
Liverpool	Royal Infirmary	1.35
London	St Barts & The Royal London	1.79
London	Guys & St Thomas' Hospital	1.70

Table 2.1: (continued)

Hospital		Estimated population (Millions)
London	Hammersmith & Charing Cross Hospitals	1.30
London	Kings College Hospital	1.01
*London	Royal Free, Middlesex, UCL Hospitals	1.43
Manchester	Hope Hospital	0.94
Middlesbrough	James Cook University Hospital	1.00
Newcastle	Freeman Hospital	1.31
Norwich	James Paget Hospital	0.84
Nottingham	Nottingham City Hospital	1.16
Oxford	Churchill Hospital	1.80
Plymouth	Derriford Hospital	0.55
Portsmouth	Queen Alexandra Hospital	2.00
Preston	Royal Preston Hospital	1.48
Reading	Royal Berkshire Hospital	0.60
Sheffield	Northern General Hospital	1.75
Shrewsbury	Royal Shrewsbury Hospital	0.40
Southend	Southend Hospital	0.35
Stevenage	Lister Hospital	1.25
Sunderland	Sunderland Royal Hospital	0.34
Swansea	Morrison Hospital	0.70
Truro	Royal Cornwall Hospital	0.36
Wirral	Arrowe Park Hospital	0.53
Wolverhampton	New Cross Hospital	0.49
Wrexham	Maelor General Hospital	0.32
York	York District Hospital	0.39
Northern Ireland		1.69
Antrim	Antrim Hospital	
Belfast	Belfast City Hospital	
Newry	Daisy Hill Hospital	
Tyrone	Tyrone County Hospital	
Ulster	Ulster Hospital	
Scotland	(via the Scottish Registry)	5.10
Aberdeen	Aberdeen Royal Infirmary	
Airdrie	Monklands District General Hospital	
Dunfermline	Queen Margaret Hospital	
Dumfries	Dumfries & Galloway Royal Infirmary	
Dundee	Ninewells Hospital	
Edinburgh	Royal Infirmary	
Glasgow	Glasgow Royal Infirmary & Stobhill General Hospital	
Glasgow	Western Infirmary	
Kilmarnock	Crosshouse Hospital	
Inverness	Raigmore Hospital	

*Renal unit included in the report for the first time.

Future coverage by the Registry

From the analyses presented here, it can be seen that the report on the 2005 data covers over 90% of the UK with further centres joining

with data for 2006. With the recommendation in the Renal National Service Framework (NSF) that all renal units should participate in audit through the Registry, all renal units in England, Wales and Northern Ireland have invested in the IT technology and local support

Table 2.2: Progress in centres not included in this report

Hospital (Indicates IT system used by hospital)		Estimated population (millions)
(a) Centres submitting data for 2006		
Stoke	North Staffs (Cybernius system)	0.70
Manchester	Royal Infirmary (CCL clinical vision)	2.51
(b) Centres hoping to submit data for 2007		
Canterbury	Kent & Canterbury – Renalplus	0.91
London	St George's (CCL clinical vision)	
London	St Mary's Paddington (Proton)	0.81

infrastructure to undertake returns to the UK Registry. To support the Renal Registry, continuing local investment is required in the additional local resources to maintain the clinical data within these systems.

The Health Care Commission (HCC) wishes to use the Registry as one vehicle for monitoring implementation of the NSF.

There are 3 new renal units that already have been/or are in the process of being set up:

1. Aintree (previously a satellite of the Liverpool renal unit) will be submitting data via Liverpool.
2. Cheshire (previously a satellite of the Wirral renal unit) will be submitting data via Liverpool.
3. Colchester.

Centres submitting 2006 and 2007 data

The renal units shown in Table 2.2 plan to have their IT systems setup and running in time to submit 2006 data. By the end of 2007 all adult renal units will have Registry compatible renal IT systems.

Completeness of returns for four important data items

The Registry has again included a table of completeness for four of the important data items for which it has been trying to improve returns. Centres have been ranked on their average score (Table 2.3). Ethnicity, date first seen by nephrologist and co-morbidity are not mandatory items in the Scottish Renal Registry returns so these centres have been listed separately.

Table 2.3: Completeness of data returns

Centre	Ethnicity	Primary diagnosis	Date 1st seen	Co-morbidity	Average completeness	Country
Dorset	100.0	100.0	100.0	98.0	99.5	England
Nottingham	99.3	100.0	98.6	98.6	99.1	England
Ulster	100.0	100.0	90.0	100.0	97.5	NI
Swansea	99.0	99.0	93.8	95.9	96.9	Wales
Bradford	93.8	95.4	100.0	95.4	96.2	England
Gloucester	100.0	95.2	91.9	96.8	96.0	England
Tyrone	100.0	91.7	91.7	100.0	95.8	NI
York	97.7	93.0	90.7	90.7	93.0	England
Wolverhampton	100.0	100.0	97.8	69.6	91.8	England
Basildon	93.3	90.0	90.0	93.3	91.7	England
Newry	100.0	92.9	32.1	100.0	81.2	NI
Portsmouth	96.1	94.1	91.5	28.8	77.6	England
Belfast	100.0	73.2	37.2	99.3	77.4	NI
Antrim	97.6	100.0	9.5	100.0	76.8	NI
Bangor	68.4	97.4	89.5	47.4	75.7	Wales
Sheffield	75.9	100.0	97.4	28.5	75.5	England

Table 2.3: (continued)

Centre	Ethnicity	Primary diagnosis	Date 1st seen	Co-morbidity	Average completeness	Country
Leicester	93.3	83.9	58.9	61.2	74.3	England
Newcastle	96.8	98.9	97.8	2.2	73.9	England
L Hammersmith & CX	100.0	93.9	0.0	100.0	73.5	England
L Kings	85.1	98.6	9.9	98.6	73.0	England
Middlesbrough	98.6	98.7	90.5	0.0	71.9	England
Ipswich	81.7	98.3	94.9	8.3	70.8	England
Bristol	86.3	76.6	60.0	57.1	70.0	England
Truro	43.8	81.3	65.6	84.4	68.7	England
L St Barts	95.0	100.0	0.0	79.4	68.6	England
Carlisle	100.0	100.0	0.0	70.0	67.5	England
Sunderland	89.7	100.0	0.0	75.9	66.4	England
Stevenage	100.0	100.0	59.6	1.0	65.2	England
Chelmsford	12.5	100.0	47.5	100.0	65.0	England
Leeds	45.1	61.6	88.3	59.1	63.5	England
Norwich	24.0	99.2	27.3	100.0	62.6	England
Derby	62.0	97.2	1.4	84.5	61.3	England
Cambridge	77.7	100.0	60.2	0.0	59.5	England
Manchester West	93.8	100.0	0.0	24.0	54.5	England
Liverpool	70.7	98.8	0.0	41.5	52.7	England
Hull	7.9	99.2	1.6	95.2	51.0	England
Dudley	100.0	100.0	0.0	0.0	50.0	England
Redding	100.0	100.0	0.0	0.0	50.0	England
Southend	57.1	85.7	0.0	57.1	50.0	England
Shrewsbury	97.7	100.0	0.0	0.0	49.4	England
Birm Heartlands	97.6	99.2	0.0	0.8	49.4	England
Oxford	84.6	95.5	1.3	14.7	49.0	England
Birm QEH	97.9	82.5	0.0	0.0	45.1	England
Preston	83.1	96.6	0.0	0.0	44.9	England
Coventry	75.3	100.0	0.0	0.0	43.8	England
Wirral	72.7	100.0	0.0	0.0	43.2	England
L Guys	56.8	100.0	0.0	2.7	39.9	England
Exeter	17.1	60.4	45.0	25.2	36.9	England
Plymouth	36.8	100.0	0.0	0.0	34.2	England
Cardiff	15.2	93.8	0.6	20.2	32.5	Wales
Clwyd	11.1	100.0	0.0	0.0	27.8	Wales
Brighton	22.2	88.0	0.0	0.0	27.5	England
Carshalton	30.6	75.6	0.6	3.3	27.5	England
L Royal Free	94.0	0.8	0.0	0.0	23.7	England
Wrexham	11.6	51.2	0.0	0.0	15.7	Wales
Scotland						
Aberdeen	1.6	3.2				Scotland
Airdrie	92.3	84.6				Scotland
Dumfries & Galloway	0.0	66.7				Scotland
Dundee	94.7	94.7				Scotland
Dunfermline	4.5	72.7				Scotland
Edinburgh	1.0	77.2				Scotland
Glasgow RI	1.6	86.3				Scotland
Glasgow WI	2.0	83.8				Scotland
Inverness	0.0	95.4				Scotland
Kilmarnock	0.0	64.3				Scotland

Software and links to the Registry

It is apparent that there are now 13 systems in use by renal units, some of them commercial and some in-house. The Registry has worked with the relevant companies to provide appropriate software links to the Registry. As new data items (eg those relating to vascular access) are defined and the need for collection by the Registry accepted, there will be a continuing requirement that these companies provide the necessary enhancements to their systems to permit collection of these items and maintenance of an interface with the Registry for the new items. The NHS Information Centre has developed a National Renal Dataset, with the intention that collection of these data items within electronic care records provided by Local Service Providers under Connecting for Health will be mandatory; the feasibility of collection of data items defined within the dataset is now being tested using existing renal unit IT systems and this project will also require software development to permit collection of data items not currently collected by the Registry.

Paediatric Renal Registry links

In the UK in 2005 there were 768 patients under 18 years old who were on renal replacement therapy. As most of the 13 UK paediatric renal units are small, the British Association of Paediatric Nephrology (BAPN) was able to set up its own database to register data on a partially manual basis. As in previous years, this report includes separate analyses from these data (Chapters 13, 14, 15). In order to integrate them with the adult Registry and also benefit from funded resources for data management, the BAPN has asked the adult Registry to develop the means to collect the paediatric data electronically. This process of integration of paediatric data is proceeding slowly.

Links with other organisations

The UK Renal Registry has been active in supporting the Renal Association Standards Sub-committee in the production of the Standards document. It now participates in the

Renal Association Clinical Affairs Board to support activity in all clinical areas and in informing new standards.

Close collaboration has developed with UK Transplant (UKT), in conjunction with the British Transplantation Society, to produce analyses utilising the coverage of both the UKT and Renal Registry databases. The 2005 report included a full chapter of these analyses. New analyses for 2006 include the survival benefit of patients after having received a renal transplant when compared to a patient who remained on the transplant waiting list. The results were presented at the British Transplantation Society meeting and a paper is in preparation.

Support has been given to the Department of Health (DH) in acquiring the basic data necessary for the future planning of renal services. The Registry participated in providing data to formulate the advice to ministers in the Renal NSF. It is also working with the DH Data Standards Board developing a Renal Dataset for the national IT spine. The Registry is part of the Kidney Alliance. A collaboration between the Renal Association and the Registry, the British Renal Society, the British Transplantation Society, the National Kidney Federation and others, was selected and funded by the Health Care Commission to write the scope for audit of implementation of the Renal National Service Framework and of renal care in the UK.

Web-based collection of an extended dataset by the Health Protection Agency (HPA) on patients on RRT with Methicillin Resistant Staphylococcus Aureus (MRSA) bacteraemia was piloted in eight renal units in 2006–7. This programme is now being extended to the whole of England. The Registry has collaborated with the HPA and the Cleaner Hospitals Team of the Department of Health for England in providing details of main and satellite units, to ensure that all patients on RRT developing MRSA bacteraemia can be accurately identified. The Registry will provide denominator data for future analyses of MRSA rates and will be able to produce reports jointly with the HPA.

The Registry is exploring ways of linking the dataset collected direct from renal unit IT

systems with NHS data items such as the Hospital Episode Statistics database, now held by the Secondary User Service. Development of such linkages, using NHS number as a unique identifier, will require approval under Section 60 of the Health and Social Care Act. This would allow the Registry to incorporate analyses, for instance, of hospitalisation rates or of co-morbidity derived from hospital discharge codes.

The UK Registry sends fully anonymised data to the European Renal Association Registry. Several representatives have participated in discussions regarding the ERA nephroQUEST programme for European countries, which intends to initiate quality initiatives, similar to many of those already undertaken by the UK Renal Registry. The nephroQUEST initiative has recently been granted funding by the European Union; the first phase will involve the specification and development of a standardised renal IT data interface for electronic exchange of data (HL7v3). The nephroQUEST group is also investigating the feasibility of funding and co-ordinating pan-European collaboration in anaemia, mineral metabolism and cardio-vascular risk studies.

The Registry has links with the new Swiss Renal Registry and while this is in the process of being established; Dr Dorothea Nitsch has been seconded to work in the UK and collaborates closely with the UK Registry. Collaborative work is also being undertaken with the Australian and Canadian renal registries.

Dr Simon Watson has obtained a one year consultant level fellowship grant from the NHS Institute for Innovation and Improvement. He will be collaborating with the UK Renal Registry and leading the quality improvement initiative.

Commissioning of renal services and PCTs

A specialist renal commissioner representative (Jenny Scott) has joined the Registry Committee to inform on the support provided by the Registry in assisting Specialist commissioning consortia and individual Primary Care Trusts with appropriate data and analyses. An

executive summary of this Report will be prepared for Commissioners.

Contact has also been made with the East Midlands Public Health Observatory, which the Department of Health has identified to be the lead PHO for renal services in England.

The Registry has reported some demographic analyses based on Local Authority and also PCT areas. Only some of the boundaries of the PCTs and Local Authorities in England are similar. The Office for National Statistics is in the process of re-aligning the PCT boundaries with those of Local Authorities and hopes to complete this process in 2007.

The Registry and clinical governance

There has been debate within the Renal Association Trustee and Executive Committees, the Clinical Affairs Board, the Registry Board and Committee, about the Registry's responsibilities under the principles of clinical governance, particularly if an individual renal unit appears to be under-performing on one or more key measures of clinical activity.

The Registry Report is sent to the Chief Executives of all Trusts in which a renal unit is situated, since the responsibility for clinical governance within the Trust lies formally with the Chief Executive.

In the event that Registry analyses of data from a renal unit give rise to professional concern (eg mortality, or transplantation rates), the data will first be validated internally by the Registry and then the source data checked with the reporting renal unit.

If the findings and analyses are robust and concern appears warranted, the Registry Chairman will notify the President of the Renal Association, who will write to explain matters to the Clinical Director or Specialty Lead of the relevant unit, asking that this information be passed to the Chief Executive of the Trust concerned and also to the Clinical Governance lead for that Trust. Written evidence of the internal hospital transfer of information should be received by the Renal Association within 8

weeks. If such evidence is not forthcoming the President will write to the Medical Director and Chief Executive of the Trust. The Renal Association can offer support (in terms of senior members providing advice) if requested by the Medical Director.

Anonymity and confidentiality

There has been pressure for the Renal Registry to cease the anonymous reporting of results and analyses and to identify the individual renal centres. The removal of anonymity aids the development of comparative audit and may assist learning from best practice, as well as allowing public accountability. In 2002, anonymity was removed from all the adult data except for the survival figures in individual renal units.

In the event, progress has been slow in improving the co-morbidity and ethnicity returns essential to allowing a meaningful comparison of patient survival between renal units that is corrected for case mix. Following discussion with the Renal Clinical Directors Forum there was overwhelming support for removing anonymity even if co-morbidity returns remain poor. This year, for the first time, patient survival in the named centres is reported.

The 'Health and Social Care Act 2001': section 60 exemption

The Registry has been granted temporary exemption by the Secretary of State to hold patient identifiable data under section 60 of the Health and Social Care Act. This exemption allows the registration of identifiable patient information from renal units without first asking the consent of each individual patient, avoiding a breach of the common law on confidentiality.

This exemption is temporary and is reviewed annually. The progress towards collection of anonymised data or obtaining permission of the individual patient is monitored by the Patient

Information Advisory Group (PIAG). The second annual report on progress by the Registry towards anonymisation has been submitted to the PIAG and the third review is due in March 2007.

Support for renal services in Connecting for Health – the National Programme for IT

Many renal units are concerned about support for existing IT systems under the National IT Programme. In addition, there is also concern about retaining existing functionality in any new IT system. Support for the National Renal Dataset and existing renal systems has been included in the Output Based Specification (OBS) contract for renal services and the full text is provided in Appendix F in the 2005 Report. Section 167 within the contract deals with provision of IT for renal services and has been signed by all the regionally based Local Service Providers (LSPs) as a component of the National IT Programme.

As mentioned earlier, the Registry has worked with the DH, Connecting for Health, the NHS Information Centre and BT (who provide the national spine), in the specification of the National Renal Dataset that all LSP systems will be required to support. This dataset has now been finalised and submitted to the Information Standards Board for approval.

Support for renal systems managers and informatics staffs

In 2005, the Registry provided a forum for a renal informatics meeting supporting development of renal IS & IT staff. Topics included; a discussion on current informatics, health informatics professionalism (eg UKCHIP), agenda for change and informatics related job profiles. In 2006, a renal IS meeting was run by Connecting for Health and the Registry is planning a follow on meeting for September 2007.

Interpretation of the data within the report

It is important to re-emphasise that for the reasons outlined below, caution must be used in interpretation of any apparent differences between centres.

As in previous reports, the 95% confidence interval is shown for compliance with a Standard. The calculation of this confidence interval (based on the Poisson distribution) and the width of the confidence interval depends on the number of values falling within the Standard and the number of patients with reported data.

To assess whether there is an overall significant difference in the percentage reaching the Standard between centres, a χ^2 test has been used. Caution should be used when interpreting 'no overlap' of 95% confidence intervals between centres in these presentations. When comparing data between many centres, it is not necessarily correct to conclude that two centres are significantly different if their 95% confidence intervals do not overlap. In this process, the eye compares centre X with the other 65 centres and then centre Y with the other 64 centres. Thus, 129 comparisons have been made and at the commonly accepted 1 in 20 level at least 6 are likely to appear 'statistically significant' by chance. If 65 centres were compared with each other, 2,080 such individual comparisons would be made and one would expect to find 104 apparently 'statistically significant' differences at the $p=0.05$ level and still 21 at the $p=0.01$ level. Thus, if the renal units with the highest and lowest achievement of a standard are selected and compared, it is probable that an apparently 'statistically significant result' will be obtained. Such comparisons of renal units selected after reviewing the data are statistically invalid. The Registry has therefore not tested for 'significant difference' between the highest achiever of a standard and the lowest achiever, as these centres were not identified in advance of looking at the data.

The most appropriate way of testing for significance between individual centres, to see where the differences lie, is not clear. The commonly used Bonferroni test is not applicable to these data, since the individual

comparisons are not independent. In several Chapters, funnel plots are used to identify significant outliers outside 2 and 3 standard deviations (see Chapters 3, 4, 8, 9 and 12). The Registry is investigating further methods of performing such comparisons.

In Chapters 3 and 4, charts are presented to allow PCTs and other organisations representing relatively small populations to assess whether their incidence and prevalence rates for renal failure are significantly different from that expected from the age and ethnic mix of the population they serve.

Future potential

Support for Renal Specialist Registrars undertaking a non-clinical secondment

Through links with the Universities of Southampton and Bristol, training is available in both Epidemiology and Statistics. The Renal Registry now has the funding for 3 registrar positions. Dr Alex Hodsman and Dr Uday Udayaraj started work at the Registry in February 2006 and Dr Daniel Ford has recently been appointed to the 3rd registrar position. Dr Raman Rao, Dr Az Ahmad, Dr Alison Armitage, Dr Catherine Byrne and Dr J Rajamahesh have previously completed two years working as a Registry registrar. It is hoped that their positive experiences and publication record will encourage other registrars who are interested in undertaking epidemiological work to consider working with the Registry.

Dr Fergus Caskey organised a secondment in Berlin with the German Renal Registry and undertook a detailed comparative analysis between the UK and Germany on the factors underlying the large differences in incidence of renal replacement therapy in the two countries¹⁰.

New data collection and analysis

The survey on vascular access

Last year provided the first report of detailed UK national data on vascular access provision. The 6 month and 1 year follow up results from this patient cohort are reported in Chapter 5.

The repeat 2006 vascular access survey is also reported in this chapter.

The report has been invaluable in establishing a base line for monitoring implementation of the Renal NSF and in identifying the obstructions to improvement in the provision of vascular access services. It highlighted the wide variations between renal units, with some units managing to start 95% of renal replacement therapy patients with definitive access and others less than 50%.

The Renal Association would like to thank everyone involved in the collection of these data and appreciate the effort required to supply it.

Surveys of facilities

After consultation with the Clinical Affairs Board and the Renal Clinical Directors Forum the Registry has carried out a fourth national renal facilities survey. The Registry has collaborated with the British Renal Society to collect data on non-medical staffing and a summary of these data have been included in this report.

Chronic kidney disease

In 2005, the Registry published a national survey of CKD patients under the care of nephrologists which has been published in the Quarterly Journal of Medicine. There is considerable interest in collecting further data on cohorts of renal patients with chronic kidney disease not receiving RRT, many renal units already hold such data in their systems. The Clinical Directors Forum have indicated they would like the Registry to collect data on all CKD stage 5 patients not on RRT and ways to implement this are being investigated.

Recent UK Renal Registry peer reviewed publications

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5. Tangri N, Ansell D, Naimark D. Lack of a centre effect in UK renal units: application of an artificial neural network model. *Nephrol Dial Transplant*. 2006; 21:743–8.
6. Feest TG, Rajamahesh J, Byrne C, Ahmad A, Ansell A, Burden R, Roderick R. Trends in adult renal replacement therapy in the UK: 1982–2002. *Quarterly Journal of Medicine* 2005;98:21–28.
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The following have been submitted for publication:

16. Byrne C, Roderick P, Steenkamp R, Ansell D, Roderick P, Feest TG. Ethnic factors in Renal Replacement Therapy.
17. Nitsch D, Burden R, Steenkamp R, Ansell D, Roderick P, Feest TG. Diabetes in patients with established renal failure: demographics, survival and biochemical parameters.

18. Rao AVR, Ansell D, van Schalkwyk D, Feest TGF. Peritoneal dialysis technique survival in the UK: A UK Renal Registry data analysis.
19. Rao AVR, Ansell D, Steenkamp R, Williams AJ, Dudley CRK. Effect of 1st Year Renal Graft Function on Post Transplant Hemoglobin, Blood Pressure and Bone Metabolism: Data from UK Renal Registry.
4. Feest TG, Byrne C, Ahmad A, Roderick P, Webber S, Dawson P. The Provision of Renal Replacement Therapy in the UK 2002. Report for the Department of Health, 2004.
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Commissioned research and reports

1. Feest T, Rajamahesh J, Taylor H, Roderick P. The Provision of Renal Replacement Therapy for adults in the UK 1998. 1998 National Renal Survey, Report for Department of Health.
2. Roderick P, Armitage A, Feest TG, *et al.* An evaluation of the effectiveness, acceptability, accessibility and costs of renal replacement therapy in renal satellite units in England and Wales. Report for Department of Health, 2003.
3. Roderick P, Davies R, Jones C, Feest T, Smith S, Farrington K. Simulation model of renal replacement therapy: predicting future demand in England. HTA report 2003.

Distribution of the Registry Report

The report will also be distributed to Strategic Health Authorities and all PCTs in England and Commissioners throughout the UK.

Further copies of the report will be sent to individuals or organisations on request: a donation towards the £15 cost of printing and postage will be requested. CDs will also be available. The full report may be seen on the Registry website – www.renalreg.org.